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**Developing and Validating a Health-Related Quality of Life Measure for People
with Aphasia**

By

Dirusha Moodley

A Thesis

Submitted to the Faculty of Graduate Studies
through the Department of Biological Sciences
in Partial Fulfillment of the Requirements for
the Degree of Master of Science
at the University of Windsor

Windsor, Ontario, Canada

2019

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Developing and Validating a Health-Related Quality of Life Measure for People with
Aphasia

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June 19, 2019

DECLARATION OF ORIGINALITY

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ABSTRACT

Aphasia is a neurological disorder resulting from damage to the brain. Individuals with aphasia experience deficits in language-based abilities, such as reading, writing, speech comprehension and/or speech production. These limitations reflect in the population's social and personal lives, with individuals often reporting fewer social contacts, fewer social activities and increased feelings of isolation, social exclusion, anxiety and depression. Considering this, efforts must be made to increase the support and accessibility for this population. Integral to gauging the efficacy of these initiatives is the assessment of health-related quality of life (HRQoL). There are currently several measures used to evaluate HRQoL in people with aphasia. Each measure provides an evaluation of HRQoL from a broad perspective. However, several shortcomings cause these measures to lack sensitivity to the specific problems faced by this population, particularly with regard to communication. Stemming from this, the primary objective of this study was to design and validate an accessible HRQoL measure for people with aphasia while the secondary objective was to determine how individuals with aphasia score on this measure and the well-established SAQOL-39 compared with a matched control group. While this new measure demonstrates favorable properties, findings from the analyses of reliability, construct validity and concurrent validity have informed some essential changes. Once these changes have been made, these properties will be re-evaluated in a larger population. Consistent with the hypothesis, the findings from a Mann-Whitney U test indicate that participants with aphasia scored lower on both measures of HRQoL compared with a matched control group. Overall, this study served as an essential step in the development of this measure. The findings provide us with a more comprehensive understanding of how communication loss can impact an individual's life and help us pinpoint how to better aid this population.

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Introduction

According to the World Health Organization Quality of Life (WHOQOL, 1998), quality of life (QoL) is defined as “individuals’ perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.” More simply, QoL refers to an individual’s subjective assessment of their personal well-being (Spaccavento et al., 2014). The expansive nature of quality of life as a concept has advanced the development of many well-established global scales that are suitable for a wide range of individuals. While effective in evaluating QoL from a general perspective, problems arise when considering the sensitivity of these global measures to the hardships faced by specific populations.

As a result of this shortcoming, more targeted health-related quality of life (HRQoL) scales are used to evaluate the impact of an individual’s medical disorder and treatment on functioning in relevant areas of life (Kaplan & Ries, 2007). Although often used interchangeably with the term QoL, general QoL measures are much broader and aim to capture an individual’s assessment of their own well-being across all life domains whereas HRQoL represents a sub-set of this (De Civita et al., 2005). HRQoL can be broadly categorized into two distinct types: generic HRQoL measures and condition-specific HRQoL measures (Spieth & Harris, 1996). Generic HRQoL measures are applicable to a wide range of populations with medical disorders (Varni, Seid, & Kurtin, 1999). This allows for comparison with other medical conditions and plays an integral role in cost-effectiveness analysis, which in turn guides policymakers in allocating resources to various programs and interventions (Kaplan & Ries, 2007). Condition-specific measures are used to assess the impact of a condition in a specific population of individuals. Although these measures are not effective in comparing HRQoL across populations,

they are much more sensitive to the specific condition than generic measures and enable clinicians to determine the extent to which an individual's condition impacts their life (Varni et al., 1999; Kaplan & Ries, 2007). Condition-specific measures can also be used to track an individual's progress over the course of their medical condition or any changes that accompany therapeutic interventions (Kaplan & Ries, 2007).

Considering the contributions of both types of measures, it is clear that a condition-specific measure would be most beneficial when evaluating HRQoL in a specific clinical population. This applies to people with aphasia. Aphasia is a language disorder resulting from damage to the brain; specific causes include neurodegenerative diseases, brain trauma, brain tumours and most commonly, stroke (Clark, 2011; Bahia & Chun, 2014). Impairment in communication and language abilities resulting from brain damage are widely recognized symptoms in people with aphasia. More specifically, individuals may experience difficulties in areas such as reading, writing, speech comprehension, and speech production (Ketterson et al., 2008). These limitations often result in adverse effects on many aspects of an individual's life. When compared to their non-aphasic peers, people with aphasia report fewer social contacts, engagement in fewer social activities and greater dissatisfaction with the social activities in which they do participate (Cruice, Worrall, & Hickson, 2006). An in-depth analysis of social participation from the perspectives of people with aphasia was conducted using a qualitative evaluation of diary entries over a two week period and a transcription from a semi-structured interview at the end of the two weeks. A focus group, including all individuals that participated in the study, was used as a means to confirm the researchers' findings. These findings suggest that individuals' dissatisfaction with their social activities results from their desire to have greater fulfillment in their social activities rather than a greater number of activities (Dalemans,

Witte, Wade, & Heuvel, 2010). However, many barriers to participation in community activities persist for this population (Howe, Worrall, & Hickson, 2008). As a result, isolation and social exclusion in a variety of settings is a common experience (Dalemans et al., 2010; Parr, 2007). In addition to this, people with aphasia report anxiety and depression that appear to be related to experienced language deficits (Døli, Helland, & Helland, 2017). Collectively, these findings highlight the impact that communication can have on the well-being of these individuals and point to its significance when assessing HRQoL.

However, there are few scales that account for the concerns presented above. In the past, a substantial volume of research has been dedicated to examining QoL in people with stroke, yet a shortage of such has addressed people with aphasia (Bose, McHugh, Schollenberger, & Buchanan, 2009). Although the prevalence of aphasia in stroke patients is significant (Dickey et al., 2010), individuals with aphasia are often not included in stroke-related research because of difficulties in producing and understanding language (Bose et al., 2009). When they are included, the interviewer must account for these difficulties and adjust the measures accordingly. These deviations from the standardized methods of administration cause the validity of the assessment to be called into question (Hilari & Byng, 2001).

As an alternative to this, researchers use proxies or surrogate respondents, such as caregivers, physicians or clinicians, in order to gauge an individual's quality of life (Manders, Dammekeens, Leemans, & Michiels, 2009). However, there is considerable debate surrounding the usage of proxies when evaluating HRQoL in people with aphasia. It has been demonstrated that the self-reported HRQoL ratings of people with aphasia do not correlate with proxy ratings from speech language pathologists or significant others (Cranfill & Wright, 2010). These findings extend to various family members and friends, indicating that proxies should not be

used as an alternate means of evaluating HRQoL in people with aphasia (Cruice, Worrall, Hickson, & Murison, 2005). However, other studies have found that proxies can be used to reliably evaluate HRQoL when the individual with aphasia is unable to self-report, but that proxies tend to score people with aphasia as having a lower HRQoL than people with aphasia score themselves (Hilari, Owen, & Farrelly, 2007; Ignatiou, Christaki, Chelas, Efstratiadou, & Hilari, 2012). Collectively, these findings highlight that proxies should only be used in scenarios in which self-reporting is not feasible.

The above notwithstanding, it is not uncommon for researchers to use proxies and generic HRQoL measures to evaluate people with aphasia. In a population-based study investigating the relationship between 60 diseases and 15 conditions and caregiver-assessed preference-based HRQoL, it was determined that aphasia displays the largest negative relationship to HRQoL, indicating that HRQoL was most impacted in this population (Lam & Wodchis, 2010). This study emphasizes the value of using proxies and generic measures in order to maintain consistency when evaluating and comparing individuals across various clinical populations. As previously stated, information gathered from these measures provides insight when performing cost-effectiveness analyses and making decisions regarding potential interventions (Lam & Wodchis, 2010). However, these generic measures cannot provide the sensitivity or accessibility that are vital in order to adequately investigate the quality of life of a specific population. For this reason, measures are being taken to adapt condition-specific scales that are more easily accessible for individuals with aphasia (Bose et al., 2009). The creation of the Stroke-Specific Quality of Life scale (SS-QOL; Hilari & Byng, 2001) was a necessary first-step in the advancement of aphasia-specific measures.

The SS-QOL is a self-report HRQoL measure that was developed to account for limitations detected when generic HRQoL measures are administered to patients with stroke (Williams, Weinberger, Harris, Clark, & Biller, 1999). These limitations are twofold. The first limitation pertains to content validity or how well the questionnaire represents the construct that it is intended to measure (Field, 2013). When using generic measures to evaluate stroke patients, the content validity of the domains/categories and items of the measures are no longer applicable (Williams et al., 1999). This finding suggests that generic measures may not include domains that gauge concerns surrounding stroke patients (i.e. language, mobility, thinking, vision) or items that effectively measure their level of functioning. The second limitation is that these measures may not demonstrate sensitivity to change, making it difficult to track each individual's progress over time (Williams et al., 1999). To account for these deficits, the researchers used qualitative data from interviews with stroke patients in order to generate the items and domains of the SS-QOL. After assessing the measure using exploratory factor analysis (EFA), Cronbach's alpha and sensitivity to patient-reported progress, 49 items were established across the following 12 domains: personality, family roles, language, energy, mobility, vision, self-care, social roles, mood, thinking, productivity and upper extremity function (Williams et al., 1999). This measure is separated into two distinct sections with each item scored on a 5- point Likert scale. On the first part of the measure, the scale ranges from *couldn't do it at all* to *no trouble at all* while the second part of the measure ranges from *strongly agree* to *strongly disagree* (Williams et al., 1999). An example of an item from the first part of the measure is "In the past week, did you lose your balance when bending over or reaching for something?" An example of an item from the second part of the measure is "In the past week, my physical condition interfered with my family life."

To enhance the use of the SS-QOL for people with aphasia, modifications were made to increase accessibility by creating a way to administer the measure in interview-format and reducing long items (Hilari & Byng, 2001). A second modification was the addition of 4 aphasia-related items to increase the measure's content validity. These 4 items pertain to the experience of a person with aphasia, specifically addressing problems with understanding others, problems with decision-making, and the impact that language abilities have on their social and family roles (Hilari & Byng, 2001). The final modification was a change to the scale in the second part of the measure, to range from *definitely yes* to *definitely no* (Hilari & Byng, 2001). Collectively, these modifications were made to create a measure that is more useful for people with aphasia and ultimately served as the basis for the development of the Stroke and Aphasia Quality of Life (SAQOL) scale, discussed shortly. When evaluating people with aphasia, items that address communication and language abilities are crucial, yet many HRQoL measures fail to consider this. Together, the broad nature of the SS-QOL and the inclusion of the language domain cause this measure to be much more sensitive to the difficulties faced by people with aphasia than generic measures. However, this measure does not account for several areas of impact (Hilari & Byng, 2001), ultimately proving unsuccessful in conveying the entire experience of a person with aphasia and making the SS-QOL most optimal for individuals diagnosed solely with stroke or stroke with mild forms of aphasia.

In response to these shortcomings, several aphasia-specific quality of life measures have been developed. These measures vary in their use, ranging from broad to specific with regard to the perspective they provide. The most frequently used measures include the Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39; Hilari, Byng, Lamping, & Smith, 2003), the Quality of

Communication Life Scale (QCL; Paul et al., 2004) and the Assessment for Living with Aphasia (ALA; Simmons-Mackie et al., 2014). Each of which will be discussed in detail shortly.

The SAQOL-39 (see Appendix A) is a self-report, interview-administered measure that was modified from the SS-QOL in order to better assess individuals with aphasia (Hilari et al., 2003). Preceding the establishment of the SAQOL-39 was the development of the SAQOL. The SAQOL was initially composed of the 53 items of the modified SS-QOL across the 12 aforementioned domains (Hilari et al., 2003). To reiterate, 49 of the 53 items were adapted from the original SS-QOL while the remaining 4 items were added in order to enhance the measure's content validity for people with aphasia (Hilari et al., 2003). After these modifications were made, the structure of the SAQOL was evaluated using psychometric analysis, which is a series of statistical tests used to evaluate the reliability and validity of the measure. Although the SAQOL reported good internal consistency and excellent test-retest reliability with these modifications, results from principal axis factor analysis (PAF) did not provide support for the 12 hypothesized subdomains. Results from PAF also indicated that 14 items did not load, and were therefore, removed from the measure. As a result, the measure was reduced to 39 items across the following four sub-domains: physical, psychosocial, energy, and communication. The psychometric evaluation of the newly established SAQOL-39 demonstrated high test-retest reliability, internal consistency, acceptability and construct validity (Hilari et al., 2003). In addition to this, the SAQOL-39 has demonstrated high reliability and acceptability across 17 different languages (Ahmadi, Tohidast, Mansuri, Kamali, & Krishnan, 2017), providing support for its use when evaluating quality of life in a diverse population of people.

When analyzing the results of the SAQOL-39, mean scores are calculated for each of the four domains as well as the overall measure. Each item is scored on a 5-point Likert scale in

which a higher score represents a greater quality of life (Hilari et al., 2009). When compared with healthy age- and gender- matched controls, people with aphasia obtain lower QoL scores on the SAQOL-39, displaying the greatest impairment in the communication sub-domain. In addition, both the communication and psychosocial sub-domains of the SAQOL-39 demonstrate a strong correlation with aphasia severity (Bose et al., 2009). When administering the measure to stroke patients with and without aphasia, those with aphasia report a lower QoL on the SAQOL-39 even after accounting for factors such as social support, psychological distress, overall health and stroke type and severity (Hilari, 2011). Similar results are seen in a study in which a Dutch version of the SAQOL-39 was administered to three different groups of individuals. In this study, the SAQOL-39 was administered to a group of people with aphasia, a group of individuals that have acquired brain injury (ABI) without aphasia and a group of healthy, age- and gender-matched controls. Results from the SAQOL-39 demonstrated that people with aphasia reported a lower QoL when compared with the other two groups. Additionally, the group with ABI reported lower scores than the healthy control group in all domains except communication (Manders et al., 2009). The finding that people with ABI report higher scores than people with aphasia on the communication domain (Manders et al., 2009) provides reason for considering communication when assessing QoL in people with aphasia.

While these findings demonstrate the effectiveness of the SAQOL-39 in assessing QoL from a broad perspective, the structure of the measure reflects a limitation for people with aphasia. Examining the measure, it is evident that more emphasis is placed on items that address stroke than items that address aphasia, with 17 items belonging to the physical sub-domain and only 7 belonging to communication (Hilari et al., 2003). Considering the remaining 15 items, 3 of the 4 items that belong to the energy sub-domain (Hilari et al., 2003) pertain to deficits

accompanying physical disability; in this case, resulting from stroke. The remaining 11 items of the psychosocial domain (Hilari et al., 2003) are applicable to any population experiencing significant life changes, making it relevant to both people with aphasia and people with stroke. However, when looking to assess change over time in people with aphasia, it can be argued that a measure that places more emphasis on deficits associated with aphasia should be administered. Although the interview format and communication considerations of the SAQOL-39 make this measure a valuable tool when comparing stroke populations with and without aphasia, a measure that is more tailored to the aphasic population is useful when focusing on aphasia independently from stroke.

Because communication is a substantial area of impairment in people with aphasia, a QoL measure that takes communication into consideration is crucial. For this reason, the QCL is beneficial. The QCL is a measure that is used to evaluate the degree to which communication disorders impact an individual's engagement in various areas of life, including relationships, social interactions, participation in a range of activities, and quality of life. This 18-item, self-report measure looks at the impact of communication across the following three domains: confidence and self-concept (6 items), socialization and activities (7 items), and roles and responsibilities (4 items; Paul et al., 2004). The remaining item enables the individual to rate their overall QoL but is not included in the individual's score. Instructions accompanying the measure dictate that participants should consider the phrase, "Even though I have difficulty communicating" prior to reading each item. Each item is displayed in large writing on a single page in conjunction with a vertically presented 5-point Likert scale. This scale uses five equally spaced dashes in place of numbers, with the highest dash representing agreement with the statement and the lowest dash representing disagreement. In addition, simple drawings are

presented at either side of the scale in order to help individuals understand and rate each item (Paul et al., 2004). As with the SAQOL-39, mean scores are calculated for each of the three domains as well as the overall measure. Similarly, a higher score depicts a perception of higher functioning (Bose et al., 2009).

In order to pilot test this measure, the QCL was administered to a group of individuals with neurogenic communication disorders (aphasia, cognitive communication disorders, and dysarthria). According to this study, individuals with aphasia and dysarthria scored significantly lower than individuals with cognitive communication disorders. When investigating the relationship between the QCL and a general measure of psychological well-being, specifically the Affect Balance Scale (ABS), it was determined that the two measures were minimally related. However, a moderate, significant relationship was reported between the ABS and the item of the QCL that pertains to overall well-being. In addition, this measure displays adequate test-retest reliability. Collectively, these findings lead the authors to accept the QCL as a valid measure of QoL (Paul et al., 2004).

In a study evaluating QoL in people with aphasia and a group of age- and gender-matched controls, several important findings were reported. First, it was determined that people with aphasia reported lower scores on the QCL than the control group, with the socialization and activities domain being the area of greatest impairment (Bose et al., 2009). This finding illustrates the sensitivity of the QCL when evaluating QoL in people with aphasia and aids the researchers in identifying the greatest area of impact for the population at hand. Second, a strong correlation was demonstrated between the socialization and activities sub-domain of the QCL and aphasia severity (Bose et al., 2009), providing evidence for a relationship between communication problems and decline in socialization and activities. Lastly, a strong positive

relationship was seen between the communication sub-domain of the SAQOL-39 and the socialization/activities sub-domain of the QCL as well as with the QCL mean (Bose et al., 2009). This finding provides evidence that the QCL is measuring the construct that it is intended to and corroborates the finding that there is a relationship between communication and socialization. The lack of correlations seen between the SAQOL-39 and the QCL may be explained by the goal of each measure. While the SAQOL-39 provides a broad evaluation of QoL across various areas of functioning, the QCL is centered on communication specifically (Bose et al., 2009). This makes the relationship between the QCL and the communication sub-domain of the SAQOL-39 the most important consideration when looking at the relationship between the two measures.

These findings address the need for a measure to evaluate people with a range of communication disorders and the impact surrounding these disorders. However, several problems arise when considering the structure and accessibility of the QCL, particularly with regard to people with aphasia. When examining the QCL, it is clear that the items of the measure are broad and may not provoke as much reflection as other measures (Babbitt & Cherney, 2010). Consider the item “Even though I have difficulty communicating, I like to talk with people.” While this item is communication-focused, it is evident that items such as this take a more surface-level approach to QoL and may limit our ability to gauge the full impact of the disorder. This makes the measure beneficial in detecting differences between people of differing aphasia severity, but may make it difficult to understand the effect of communication difficulties on people with milder forms of aphasia. Additionally, it can be argued that more can be done to make the measure accessible to populations with communication deficits, specifically by incorporating additional pictures to explain each item more effectively. Another difficulty surrounding the QCL is the measure’s accessibility for the administrator. In order to purchase

and implement the measure, the administrator must be a registered member or certified non-member of the American Speech-Language-Hearing Association (ASHA). Specifically, the administrator must meet ASHA requirements and be a registered speech-language pathologist (SLP), audiologist, or speech/language/hearing scientist. This may not be feasible for researchers, physicians or clinicians in other areas that are looking to administer the measure to a population with a communication disorder. The final problem with the QCL is the limited psychometric evaluation compared with other measures, such as the SAQOL-39. Although the QCL is accepted as valid, results from pilot testing only report on the test-retest reliability, construct validity and within domains correlations of the measure. However, it would have been beneficial to evaluate the internal consistency of the measure, in terms of Cronbach's alpha and/or item-total correlations and additionally report on concurrent validity. Without an extensive review of the measure's psychometric properties, it is difficult to justify using this measure over more well-established scales, such as the SAQOL-39. While the QCL does have its advantages when evaluating individuals with a range of communication disorders, it is evident that researchers and clinicians can benefit from using an aphasia-specific measure when evaluating QoL in this population.

The ALA addresses this need. The ALA is an aphasia-related, self-report measure of quality of life. Specifically, this measure is used by clinicians and researchers in order to determine the impact of aphasia on daily life. The decision to design the ALA as a self-report measure stemmed from the desire to understand an individual's perception of their own QoL (Simmons-Mackie et al., 2014). Initially, the ALA was composed of 57 items derived from literature and input from individuals with experience in the field, including SLPs, people with aphasia, family members of people with aphasia and the research team. Of these 57 items, 5

pertain to the language domain, 9 to the environment domain, 13 to the personal domain, 23 to the participation domain and 2 to general QoL. The remaining 5 items are unscored but are incorporated in order to provide descriptive information about the person with aphasia. Each item was previously rated on a 9-point scale ranging from 0-4, with 0 representing never and 4 representing always (Simmons-Mackie et al., 2014). Contrary to the SAQOL-39 and QCL, the ALA is scored by calculating the total score for each of the four domains as well as the overall measure, rather than by calculating the mean score. Of the 52 scored items, 15 were removed by the researchers due to missing values, results from test-retest reliability, and feedback from focus groups. The structure of the 9-point scale was also evaluated and rearranged into a 5-point scale, ranging from 1 to 5.

The revised 37-item measure displays acceptable to high internal consistency, moderate to strong test-retest reliability for the measure domains, excellent test-retest reliability for the total score, acceptable face validity and acceptable construct validity (Simmons-Mackie et al., 2014). The construct validity of the measure was examined by determining the correlation between the ALA and the SAQOL-39, the Visual Analogue Self-Esteem Scale (VASES; Brumfitt & Sheeran, 1999) and Communication Associated Psychological Distress Scale of the Burden of Stroke Scale (BOSS CAPD; Doyle et al., 2004). Results from this analysis demonstrated moderate significant correlations between the ALA and each of the three measures, suggesting that the ALA shares constructs with these measures. Stronger correlations may not be seen due to differences in the focus of each of the questionnaires. For example, the SAQOL-39 focuses on individuals with stroke and incorporates items related to physical and energy domains. In contrast, the ALA does not include items related to physical disability and instead

focuses on the daily life experiences of an individual with aphasia (Simmons-Mackie et al., 2014).

A large advantage of the ALA is the addition of pictographic material and a conversational script to increase the accessibility of the measure (Simmons-Mackie et al., 2014). The addition of these elements served two purposes. First, to aid individuals with differing aphasia severities in understanding the items so that they are able provide more accurate responses when completing the self-report questionnaire. Second, to devise a method of administering the measure to promote consistency and give the interview a conversational feel (Simmons-Mackie et al., 2014). Another advantage is that the specificity of the measure to people with aphasia enables clinicians and researchers to grasp the extent to which aphasia affects participation in common life experiences.

However, there are also several limitations to consider. A complication surrounding the ALA is that the measure was administered by SLPs who were thoroughly trained in conversation support, ALA administration and research protocol (Simmons-Mackie et al., 2014). The difficulty with this level of training is that other clinicians or researchers may not possess the same qualifications, causing the reliability and validity of the measure to be called into question (Simmons-Mackie et al., 2014). This limitation coupled with the costliness of the measure affects its accessibility for researchers and clinicians. Lastly, the ALA is intended to be an aphasia-specific measure of daily QoL. Rather than focusing on determinants of health, the ALA focuses on emotions, commonplace experiences, and how the individual interacts with their surrounding environment. This differs from HRQoL measures, in the sense that the ALA does not focus on determining the reasoning behind QoL scores or how various factors affect overall QoL. Instead, emphasis is placed on using the measure to understand the impact of aphasia on each

individual's everyday life and to develop person-centered goals (Simmons-Mackie et al., 2014). For this reason, the ALA is most favorably used by clinicians when working individually with people with aphasia. However, it is difficult to develop a full understanding of the factors that contribute to an individual's QoL when using this measure.

The present study was focused on developing a novel, aphasia-specific HRQoL measure that takes the structure and characteristics of other measures into consideration. As previously mentioned, deficits in communication are of great importance when considering QoL in people with aphasia. For this reason, this measure is primarily focused on addressing the impact that an individual's communication has on several domains of QoL. However, an individual's physical health is often adversely affected after the incident that lead to their diagnosis of aphasia. Due to this, it is considered in this evaluation of HRQoL, but to a lesser extent than communication. As a result, the aim of this study was to develop a scale that is more specific to people with aphasia and is additionally, more comprehensive to allow for a thorough evaluation of the impact of aphasia across a greater scope.

There were two main objectives in this study. The first objective was to design and validate a novel, accessible HRQoL measure for people with aphasia. For this reason, the first objective was addressed with the research question: Is this new measure a valid and reliable tool for evaluating HRQoL in people with aphasia? The second objective was to evaluate how people with aphasia score on both the SAQOL-39 and the new HRQoL measure compared with a matched control group. For this reason, the second objective was addressed with the research question: How does a group of people with aphasia compare with an age-, gender- and education-matched control group on the SAQOL-39 and the new HRQoL measure? Answering

these two questions will enable us to make beneficial changes to the measure and determine when it can be used to track HRQoL in people with aphasia over time.

Method

The following procedures have been approved by the Research Ethics Board at the University of Windsor.

Participants

Since this study was focused on developing and validating an aphasia-specific HRQoL measure, the population of interest was people with aphasia. Individuals with aphasia were referred to us by various professionals (SLPs, physiatrists) and through word-of-mouth for participation in the Word Exchange groups (discussed shortly) run by members of Dr. Buchanan's Cognitive Neuroscience lab. Participants that were referred to participate in the Word Exchange groups were asked to complete an assessment battery, which included the SAQOL-39 and the new HRQoL measure, as part of a program evaluation. No exclusionary criteria was applied to this population.

As a result, 10 individuals with aphasia participated in this study. The sample, like the population, ranged in age, education, aphasia severity and gender. The group consisted of 3 females and 7 males, ranging from 36- 82 years of age ($M = 63.90$, $SD = 12.35$). Education level was coded with a value from 1-6, with 1 representing completion of some high school, 2 representing completion of a high school diploma, 3 representing completion of some university/college, 4 representing completion of an undergraduate/college degree, 5 representing completion of a master's degree, and 6 representing completion of a PhD or professional degree. The education level of this group ranged from 1 to 6 ($M = 3.50$, $SD = 1.90$).

In addition to participants with aphasia, a group of healthy controls were recruited through word-of-mouth. These participants were matched to the population with aphasia in terms of age, gender, and education. As a result, this group also consisted of 3 females and 7 males, ranging from 28-86 years of age ($M=63.70$, $SD=15.13$). The education level of the control group ranged from 2-6 ($M=3.70$, $SD=1.64$). Although efforts were made to find an exact match for each participant with aphasia, this was not possible in some cases. In situations such as this, individuals with similar demographics were used. Ultimately, the goal was to match the mean values for each group as closely as possible.

Each individual that participated in this study, regardless of group, was compensated with a Cineplex gift card worth \$12.

The Word Exchange

The Word Exchange is a language-based support group for people with aphasia. These groups are run by volunteers from Dr. Buchanan's Cognitive Neuroscience research lab that have received Supported Conversation for Adults with Aphasia (SCA) training. SCA training is a program that teaches individuals how to use various methods of communication, such as gestures, pictures, and keywords, to promote conversation with people with aphasia. The Word Exchange group enables members to practice communication skills, engage in conversation and participate in language-based activities with other individuals with aphasia as well as with trained volunteers. This group serves to increase confidence, promote communication and provide members with aphasia with an opportunity to meet others that have similar experiences to their own.

Measures

Each participant in this study completed the SAQOL-39 and the new HRQoL measure.

The SAQOL-39

As previously mentioned, the SAQOL-39 is a self-report, HRQoL measure that consists of 39 items across the following four domains of QoL: energy, communication, psychosocial, and physical (see Appendix A for the SAQOL-39). From these 39 items, 4 pertain to energy, 7 to communication, 11 to psychosocial functioning, and 17 items to physical functioning (Hilari et al., 2003). The SAQOL-39 is scored on a 5-point Likert scale, with 1 representing *couldn't do it at all* or *definitely yes* and 5 representing *no trouble at all* or *definitely no*. Mean scores are calculated for each of the four domains of the SAQOL-39 as well as for the overall measure (Hilari et al., 2009). The SAQOL-39 was selected because it is well-established and reports excellent test-retest reliability, internal consistency, construct validity and acceptability (Hilari et al., 2003). This measure is administered in interview format to individuals with stroke and/or aphasia, with specific instructions provided in order to maintain the standardization of the measure. These instructions include directions on how to administer the measure and includes an overview of various facilitation strategies.

The New HRQoL Measure

The new HRQoL measure is an accessible, newly constructed scale designed specifically for people with aphasia. A review of the literature on aphasia and working directly with the population were both used to derive the eight domains and 34 items encompassed in the measure. The following seven domains were extracted from a conceptual and measurement framework for QoL: personal development, self-determination, interpersonal relations, social inclusion, emotional well-being, material well-being, and physical well-being. The conceptual and measurement framework is composed of eight domains that were derived from a synthesis of international literature on QoL and then validated in cross-cultural studies (Schalock, Bonham, &

Verdugo, 2008). The rights domain was not included in this measure due to overlap with others domains related to social participation.

The remaining seven domains of the conceptual and measurement framework for QoL were incorporated into this aphasia-specific measure. Although the framework that this measure was based on was derived for people with intellectual disabilities, the researchers' findings from the international literature on QoL indicated that the fundamental domains of QoL should be the same for all individuals (Schalock et al., 2002). A study investigating factors that are associated with lower HRQoL in people with aphasia demonstrated that emotional distress, social network, and social support are important factors in HRQoL for this population (Hilari, Needle, & Harrison, 2012). This supports the inclusion of the emotional well-being, interpersonal relations, and social inclusion domains into the measure. There is also support for the importance of communication disability in HRQoL (Hilari, Needle, & Harrison, 2012), providing reason for the addition of a direct communication domain in the QoL measure. In addition to these findings, the researchers discuss activity limitations as a factor that impacts HRQoL in people with aphasia (Hilari, Needle, & Harrison, 2012). This finding supported the inclusion of a physical well-being domain into the framework of the measure. Notably, the physical well-being domain was not initially incorporated into the measure because this is an aphasia-specific measure of QoL and physical functioning is much less relevant to aphasia than stroke. However, this finding, in combination with information discussed during the first Word Exchange program provided justification for the integration of this domain into the measure. While deficits directly related to aphasia are still the primary focus of this measure, the inclusion of a related domain may provide a more comprehensive assessment of HRQoL. The remaining domains of the measure were well supported by literature and direct interaction with people with aphasia.

The following eight domains were used to construct the new HRQoL measure: emotional well-being, interpersonal relations, social inclusions, personal development, self-determination, material well-being, physical well-being and direct communication. Four items of the measure pertain to the emotional well-being domain, associated with areas of self-concept, contentment, and lack of stress (e.g., ability to enjoy activities). Five items belong to the interpersonal relations domain, which is comprised of topics such as support, relationships, and interactions (e.g. ability to maintain a romantic relationship). Three items pertain to the social inclusions domain, which addresses areas such as community roles and integration (e.g. motivation to attend events). Five items belong to the personal development domain, which consists of topics such as education, performance and personal skill (e.g. feelings of competence). Five items belong to the self-determination domain, which refers to personal goals, choices and autonomy (e.g. ability to make your own decisions). Three items belong to the material well-being domain, which encompasses areas such as employment and financial status (e.g. ability to control your own finances; Schalock et al., 2008). Three items were incorporated into the direct communication domain in order to investigate the degree to which communication deficits impact the individual's ability to read, maintain a conversation and use the telephone. Six items pertain to the physical well-being domain, which refers to areas such as health status and activities (e.g. how much you sleep; Schalock et al., 2008). See Appendix B for a breakdown of the items that correspond to each domain. The final item of the measure remains unscored, but was included to serve as a summary question at the end of the measure (e.g. Do you expect the future to be better?). This item may prove beneficial when reporting on HRQoL for a large population of people with aphasia or when working on patient-centered goals with a small group of individuals.

The new HRQoL measure is separated into two distinct parts. The first part of the measure contains 28 items and uses the introductory phrase “In the past week, have your aphasia symptoms (your ability to speak or understand language) affected your” prior to reciting each item. The information in brackets is only recited aloud in the case that the individual is having difficulty understanding the term “aphasia symptoms”. The second part of the measure contains 6 items and uses the introductory phrase “In the past week, has your physical health affected”. Similar to the SAQOL-39, all items for both sections of the measure are scored on a 5-point Likert scale, in which a higher score indicates a greater HRQoL.

After the basic structure of the measure was developed, several steps were taken in order to enhance the accessibility of the measure for individuals with aphasia. The first step in accomplishing this was to incorporate visual aids. To do this, a copyright free website was used to select several images for each item. These images, along with the item that they represent, were then presented to various individuals for pilot-testing in order to determine which image was most suitable for each item. In some cases, multiple images were selected. Pilot-testing of these images served to ensure that the images were congruent with the content of the item and beneficial in enhancing understanding. As a result, the selected visual aids were presented beneath each item with the goal of helping participants with aphasia understand each item to a greater degree.

The second step in enhancing accessibility was the creation of a visual analogue scale (see Appendix C for scaled-down Visual Analogue Scale). Similar to other measures of QoL, each item was scored on a 5-point Likert scale, with 1 representing very frequently, 2 representing frequently, 3 representing occasionally, 4 representing rarely and 5 representing never. In line with the idea of using visual aids to enhance understanding, an image of a calendar

ranging from completely full to completely empty was developed to represent each point on the scale. The idea behind creating the scale in this way was to make it easier for participants to associate meaning with each value. The intent was to place the scale next to the participant for the duration of the assessment so that they could refer back to it at any time.

The third step in enhancing accessibility was to create verbal prompts for specific items. These prompts are provided on the administrator score sheet (see Appendix D for the Score Sheet) so that they could serve as a cue if a participant is having difficulty with an item. These prompts were to be recited by the researcher/administrator of the measure, and are therefore, not included on the participant copy of the measure. This leads into the fourth step.

This measure was structured with the intention of being administered in interview-format. For this reason, administration instructions are provided as a way of maintaining standardization when conducting the measure. It is important to note that the administrator does not need experience in speech language pathology in order to conduct the measure. Although the measure is conducted in interview-format, participants are presented with a visual copy of the measure. This copy of the measure (see Appendix E for the scaled down Participant Copy of the Measure) includes each of the 34 items as well as the visual aids that were selected to represent each item. The purpose of providing participants with a visual copy of the measure is to account for the way in which each individual comprehends language; some individuals may rely on visual aids while others may not. Therefore, this visual copy can serve as a guide throughout the assessment.

Participants are able to provide responses by either verbally stating or pointing to their response on the visual analogue scale next to them. The response for each item is then recorded by the administrator on the score sheet. When scoring the measure, mean scores are calculated for each of the eight domains as well as the overall measure, resulting in nine mean scores.

Procedure

Participants with Aphasia

After participants with aphasia were recruited to the study, a test battery was administered in an accessible, agreed-upon location, such as their home, the research lab or the hospital space in which Word Exchange groups are held. This testing session took approximately 1-2 hours to complete and began with a thorough review of the consent form. Participants were presented with an aphasia-friendly consent form that detailed information pertinent to their involvement in the research, such as expectations, risks, and benefits. The instructions emphasized that all responses were completely confidential and that participant IDs would not be associated with their name or any personally identifying information at any point throughout the research process. If the individual was willing to participate in the research after going through the consent form, they were asked to provide their signature on the form, after which, the assessment session could begin.

The assessment began with a collection of demographic information pertaining to each individual's age, gender, education and job experience as well as information about their social support network. Participants were then given a series of language-based tasks that were helpful in gauging each individual's aphasia severity level. It is important to emphasize that these were not diagnostic tests, but rather tasks that helped us understand each individual's language production and comprehension level. It is also worth noting that these tasks were not performed for use in this study and will therefore, not be discussed further. Once these tasks were completed, individuals were asked to complete several measures regarding communication confidence, self-esteem, and health-related quality of life. These measures were completed as part of an intake assessment for the Word Exchange groups. As a result, the outlined procedure

will focus on the two measures that are relevant to the study: the SAQOL-39 and the new HRQoL measure. The order of administration was alternated between each participant.

The SAQOL-39 was administered in interview format, carefully following the administration instructions. This began by explaining the purpose of the SAQOL-39 followed by a description of how the measure is administered, including information regarding the transition sentence and the 5-point Likert scale. Prior to administering the actual scale, an example item was given to ensure that the participant understood the task. Once the assessment began, the participant's response to each item was recorded on the score sheet.

Similar to the administration of the SAQOL-39, the instructions were closely followed throughout the administration of the new measure. Participants were presented with the visual/participant copy of the measure as well as a copy of the visual-analogue scale. Before beginning the assessment, the researcher explained to the participant that they will be rating items on a 5-point scale, using the visual-analogue scale as an aid. It was explained that they could either recite the number aloud or point to the value on the scale when providing a response. They were then given a brief example to check for understanding. Participants were encouraged to keep the scale next to them throughout the assessment in order to refer back to it when providing responses. After this, the researcher explained to the participant that this measure is comprised of two parts, with the first part focusing on their aphasia symptoms and the second part focusing on their physical health. The researcher then went through the question stem followed by the items of the questionnaire in interview-format. The question stem was repeated before each item until it was clear that the participant understood the instructions. All responses were recorded by the researcher in the score sheet, containing the items of the measure as well as the verbal prompts for each item. If the participant had difficulty with an item, the researcher

would provide the participant with the outlined verbal prompt. Any additional prompts given or information that the participant provided was detailed in the "Notes" section of the score sheet.

Each assessment within a test battery was administered by the same researcher and each measure was accompanied with comprehensive instructions in order to maintain consistency.

Control Participants

The control participants were asked to complete a demographic questionnaire, four introductory questions on their language abilities (see Appendix F for Introductory Questions), the SAQOL-39 and the new HRQoL measure. As with the participants with aphasia, the assessment session began with the process of consent, outlining information such as purpose, expectations, benefits, and risks. If the individual was willing to participate in the study, they provided their signature on the consent form. The participant was then able to complete the measures independently due to the fact that this population did not have the same accessibility needs as the population with aphasia. However, they were encouraged to address any questions that they had with the researcher. The question stem for the new measure was modified for control participants to "In the past week, has your ability to speak or understand language affected your" in order to prevent bias when self-reporting. In total, the time taken to complete this study ranged from 10 minutes to half an hour.

Results

A total of 20 participants were recruited, 10 for each of the two groups. All individuals were included in the analysis. The demographics of each group can be found in Table 1. To reiterate, education level was coded with a value from 1-6, with 1 representing completion of some high school, 2 representing completion of a high school diploma, 3 representing completion of some university/college, 4 representing completion of an undergraduate/college

degree, 5 representing completion of a master's degree, and 6 representing completion of a PhD or professional degree.

After data from participants with aphasia was collected, several properties were examined in order to evaluate the reliability and validity of the measure; this includes internal consistency, construct validity, and concurrent validity. It should be noted that these properties were investigated only using the data from participants with aphasia. The data from control participants was only required for the Mann-Whitney U test in order to compare between the two populations. Because both measures are scored on 5-point Likert scales, all data is ordinal and therefore, nonparametric.

Table 1.

Demographics for participants with aphasia and control participants

Group	Number of Males	Number of Females	Age Range	Mean Age	Education Range	Education Mean
Participants with Aphasia	7	3	36-82	63.9	1-6	3.5
Control Participants	7	3	28-86	63.7	2-6	3.7

Internal Consistency

To evaluate the reliability of the measure in terms of internal consistency, Cronbach's alpha was calculated for each domain of the new HRQoL measure as well as for the entire measure. These findings enable us to examine whether the items of each domain are measuring the same construct. The results from this analysis can be found in Table 2.

In addition to the calculation of Cronbach's alpha, item-total correlations and inter-item correlations were analyzed. Item-total correlations represent the relationship between each item and the domain that it falls under while inter-item correlations represent the correlation between various items within a domain. The Cronbach's alpha for each domain, when a specific item within that domain is removed, was also calculated. These findings are reported in Table 3.

Table 2.

Cronbach's alpha for overall and each domain of the new HRQoL measure

Domain	Cronbach's Alpha
Direct Communication	0.725
Social Inclusions	0.830
Emotional Well-Being	0.806
Interpersonal Relations	0.678
Self-Determination	0.836
Material Well-Being	0.543
Personal Development	0.573
Physical Well-Being	0.847
Overall Measure	0.939

Note: Since Cronbach's alpha is represented as a value between 0-1, the goal is to see a value above 0.7 which indicates acceptability (Mayers, 2013). All values that are below 0.7 are indicated in bold.

Table 3.
Reliability analysis for new HRQOL measure

Domain	Items	Item-Total Correlation	Cronbach's Alpha if Item is Deleted	Cronbach's Alpha of Domain	Inter-Item Correlation Range
Direct Communication	1. Ability to maintain a conversation	0.836	0.326	0.725	0.215 - 0.714
	2. Ability to read	0.464	0.832		
	3. Ability to use the telephone	0.461	0.738		
Social Inclusions	1. Motivation to join activities	0.800	0.647	0.830	0.502- 0.725
	2. Feeling of belonging to a social group	0.687	0.781		
	3. Motivation to attend events	0.619	0.839		
Material Well-Being	1. Job/ Volunteering opportunities	0.619	-0.024	0.543	-0.012- 0.732
	2. Ability to keep a stable job/volunteer position	0.456	0.279		
	3. Ability to control your own finances	0.082	0.845		
Interpersonal Relations	1. Motivation to interact with other people	0.501	0.594	0.678	-0.512- 0.584
	2. Ability to maintain friendships	0.642	0.534		
	3. Ability to get along with your coworkers/peers	0.052	0.765		
	4. Ability to be in a romantic relationship	0.268	0.690		
	5. Ability to meet new people	0.766	0.444		

Emotional Well-Being	1. Ability to enjoy activities	0.753	0.700	0.806	0.156 – 0.735
	2. Levels of stress	0.639	0.749		
	3. Self-esteem	0.788	0.675		
	4. Happiness	0.362	0.875		
Self-Determination	1. Ability to make your own decisions	0.568	0.821	0.836	0.148 - 0.873
	2. Ability to reach your goals	0.502	0.840		
	3. Ability to meet other's expectations	0.711	0.784		
	4. Ability to express opinions	0.611	0.809		
	5. Sense of independence	0.824	0.742		
Personal Development	1. Ability to finish tasks	0.390	0.490	0.573	-0.241- 0.529
	2. Confidence in your abilities	0.544	0.362		
	3. Ability to learn new information	0.411	0.473		
	4. Feeling of competence	0.457	0.447		
	5. Ability to develop new skills	-0.084	0.703		
Physical Well-Being	1. How often you go out	0.745	0.797	0.847	0.216 - 0.911
	2. How much you sleep	0.644	0.819		
	3. Your energy	0.622	0.823		
	4. How much exercise you get	0.886	0.774		
	5. Your participation in activities	0.429	0.866		
	6. How you feel about yourself	0.530	0.840		

Note: All items that stand out have been indicated in bold for reconsideration.

Construct Validity

In order to evaluate construct validity, correlations between domains and the overall measure were analyzed. The correlation coefficients for this analysis are presented in Table 4. Principal component analysis (PCA) is another method of analyzing the structure of a measure in order to determine if any of the domains of the measure need to be condensed or items need to be extracted. Using an eigenvalue cut-off of one (Kaiser, 1960), results from PCA indicate eight components that explain 97.7% of the variance. Using a loading cut-off value of 0.4 (Mayers, 2013), all items successfully loaded onto one of the eight components. However, items 16, 23 and 28 loaded negatively onto 3, 7 and 8 components, respectively.

Table 4.
Correlations between domains and overall measure

Domain	Correlation with Overall Measure
Direct Communication	$r=0.595$ $p=0.035$
Emotional Well-Being	$r=0.691$ $p=0.013$
Material Well-Being	$r=0.346$ $p=0.164$
Interpersonal Relations	$r=0.895$ $p<0.001$
Social Inclusions	$r=0.778$ $p=0.004$
Self-Determination	$r=0.716$ $p=0.010$
Personal Development	$r=0.862$ $p=0.001$
Physical Well-Being	$r=0.494$ $p=0.073$

Note: The correlations that are not significant ($p > 0.05$) have been indicated in bold.

Concurrent Validity

To evaluate the concurrent validity of the measure, Spearman's rank correlation was used to determine the relationship between the new measure and the well-established SAQOL-39.

The purpose of this analysis was to determine how well the new measure corresponds to a validated measure composed of similar constructs (Field, 2013). Large positive correlations ($r = 0.663 - 0.782, p < 0.05$) were found between the communication sub-domain of the SAQOL-39 and the interpersonal relations, self-determination and physical well-being domains of the new QoL measure. Large positive correlations ($r = 0.675 - 0.815, p < 0.05$) were also found between

the psychosocial sub-domain of the SAQOL-39 and the emotional well-being, social inclusions, self-determination and personal development domains. A large correlation ($r = 0.840, p = 0.005$) was also seen between the energy sub-domain of the SAQOL-39 and the personal development domain of the new measure. Conversely, the physical sub-domain of the SAQOL-39 correlates negatively ($r = -0.665$ to $-0.648, p < 0.05$) with the direct communication, interpersonal relations and the physical well-being domains. Lastly, both the communication and psychosocial sub-domains of the SAQOL-39 were positively correlated with the overall score of the new measure ($r = 0.707$ and $r = 0.623$ respectively, $p < 0.05$) while the overall score of the SAQOL-39 was positively correlated with the emotional well-being and personal development domains of the new measure ($r = 0.752$ and $r = 0.675$ respectively, $p < 0.05$).

Comparison between participants with aphasia and matched controls

Lastly, the Mann-Whitney U test was used to evaluate how people with aphasia scored on both the SAQOL-39 and the new HRQoL measure compared with their matched controls. The test was used to evaluate each measure both overall and within each domain, with the two groups (people with aphasia vs matched controls) represented as the grouping variable and the HRQoL scores represented as the test variable. The results from this analysis demonstrated a significant difference between participants with aphasia and control participants with respect to QoL, both overall and for each domain. The results additionally showed that participants with aphasia scored lower in each area compared with matched controls. These findings are reported in Table 5.

Table 5.
Mann-Whitney U results for participants with aphasia and control participants

Domain	Group	Mean Rank	Significance
SAQOL-39 Physical	Group with Aphasia	4.75	U = 2.00
	Control Group	13.30	p < 0.001

SAQOL-39 Communication	Group with Aphasia Control Group	4.5 13.50	U = 0.00 p < 0.001
SAQOL-39 Psychosocial	Group with Aphasia Control Group	5.00 13.10	U = 4.00 p = 0.001
SAQOL-39 Energy	Group with Aphasia Control Group	5.00 13.10	U = 4.00 p = 0.001
SAQOL-39 Mean	Group with Aphasia Control Group	4.50 13.50	U = 0.00 p < 0.001
Direct Communication	Group with Aphasia Control Group	6.95 14.05	U = 14.50 p = 0.004
Emotional Well-Being	Group with Aphasia Control Group	7.15 13.85	U = 16.50 p = 0.006
Material Well-Being	Group with Aphasia Control Group	6.20 14.80	U = 7.00 p = 0.001
Interpersonal Relations	Group with Aphasia Control Group	6.40 14.60	U = 9.00 p = 0.001
Social Inclusions	Group with Aphasia Control Group	7.15 13.85	U = 16.50 p = 0.005
Self-Determination	Group with Aphasia Control Group	6.95 14.05	U = 14.50 p = 0.005
Personal Development	Group with Aphasia Control Group	6.95 14.05	U = 14.50 p = 0.004
Physical Well-Being	Group with Aphasia Control Group	7.05 13.95	U = 15.50 p = 0.008
QoL Mean	Group with Aphasia Control Group	6.40 14.60	U = 9.00 p = 0.002

Note: All values presented in the table are significant. The U score cut-off point for the SAQOL domains was set to 17 while the cut-off point for the new QoL domains was set to 23. These values were determined using a U-distribution table (Mayers, 2013).

Discussion

The purpose of this study was to design and validate a novel, accessible HRQoL measure for people with aphasia and to evaluate how people with aphasia score on both the SAQOL-39 and the new measure compared with an age-, gender-, and education- matched control group. As previously discussed, the SAQOL-39, QCL, and ALA all have their merits and provide unique perspectives when investigating QoL in people with aphasia. However, a thorough review of each measure points to a need for a comprehensive scale that focuses on an individual's aphasia symptoms, but also considers their physical health. This perspective is contrary to the perspective of the SAQOL-39 which focuses on an individual's physical impairments as a result of their stroke, but touches on their communication abilities. This new measure additionally aims to be accessible, for both the researcher and the participant in order to enhance participant responding.

Internal Consistency

The reliability of the measure was investigated in terms of Cronbach's alpha, item-total correlations and inter-item correlations. Cronbach's alpha serves as a measure of internal consistency in order to determine whether participant responses are consistent within each domain (Mayers, 2013). This is thought to be an indication of whether the questions within a specific domain correspond to one another. Using a cut-off value of 0.7 (Mayers, 2013), it is evident that most of the domains of the new QoL measure demonstrate acceptable internal consistency, with the exception of the interpersonal relations, material well-being, and personal development domains. At this point, a closer examination of the individual items within each domain can provide some insight into the lower values for these three areas. This can be done by looking at inter-item correlations, item-total correlations, and the Cronbach's alpha if the item is

removed. Inter-item correlations reflect the degree to which each item relates to another item within a domain while item-total correlations reflect the relationship between each item and the rest of the items that comprise that domain. Both of these analyses are thought to have a cut-off value of 0.3 (Mayers, 2013).

Referring back to the interpersonal relations domain, the Cronbach's alpha value is 0.678. Although this value is close to the 0.7 cut-off, it is worth investigating the reason it falls short. The results from the inter-item correlation matrix demonstrate low correlations between two pairs of items ($r = 0.103$ for each) and a moderate negative correlation between another pair ($r = -0.512$). Although the negative correlation is moderate, items belonging to the same domain should be related and thus, positively correlated. Looking at each of these item pairs, the one item in common is the "ability to get along with your coworkers/peers". This item additionally had an item-total correlation of 0.052, far lower than the cut-off value of 0.3. Lastly, the Cronbach's alpha with the item removed increases the value from 0.678 to 0.765 which now exceeds the cut-off value. Examining the other two domains in the same way, the "ability to control your own finances" item of the material well-being domain and the "ability to develop new skills" item from the personal development domain yield similar findings. The removal of the finances item from the material well-being domain would increase the Cronbach's alpha value from 0.543 to 0.845 while the removal of the new skills item from the personal development domain would increase the value from 0.573 to 0.703. Taken together, these findings elicit some consideration for the removal of these three items.

However, the removal of an item depends on more than one finding. Consider the item "ability to read" from the direct communication domain and the item "happiness" from the emotional well-being domain. While both items report an inter-item correlation below cut-off

and a Cronbach's alpha value that increases with their removal, their item-total correlations are sufficient. Since the Cronbach's alpha for both domains are already above cut-off, additional evidence is needed to justify their removal. In situations such as this, an evaluation of construct validity can be very beneficial.

Construct Validity

In this study, construct validity was evaluated in two ways. The first way was an assessment of the Spearman's rank correlation between each domain and the overall score of the measure. The results from this analysis demonstrated moderate to strong correlations between each domain and the overall measure, indicating consistency in the structure of the scale. However, the physical well-being and material well-being domains resulted in the lowest correlations ($r = 0.494$ and $r = 0.346$, respectively) with the overall score. In addition to this, both domains demonstrated non-significant correlations with the overall score. This may be a result of a variety of factors. With regard to the physical well-being domain, it is possible that the moderate correlation coefficient may be a result of the construct being measured. While the majority of the measure focuses on communication, a small portion is dedicated to physical health. It is reasonable to conclude that this domain may be more weakly correlated with the total score compared with the other domains since it measures a different construct. With regard to the material well-being domain, it is sensible to attribute this finding to the "ability to control your own finances" item. However, the removal of this item does not improve the correlation coefficient or significance value of this domain. This finding calls the other two items of the domain (items 14 and 15) into question and may point to the elimination of the entire domain. The removal of this domain may be justified by the fact that two out of ten participants omitted a response for item 14 and three out of ten omitted a response for item 15. Another factor that may

have contributed to the findings of these two domains may be the sample size of the population. While the sample size most likely did not have a large effect on the correlation coefficient, it may have had an impact on the significance values obtained.

The second method of evaluating construct validity was a PCA. A PCA is an exploratory method of evaluating the structure of a measure (Mayers, 2013). Due to the small sample size of the population, the results of this analysis are approached with caution and only used to corroborate findings from other analyses. As a result, attention should be drawn to the negative factor loadings on various components. Typically, a negative factor loading is expected in situations where an item is phrased in reverse (Field, 2013). Since this was not the case for any of the items, this finding is problematic. Looking at items 16, 23, and 28, it is evident that these are the same three items with poor findings on the reliability analyses, providing additional support for their removal from the measure. The removal of item 28 reduces the component number to seven. However, the results from PCA should not dictate any changes to the internal structure of the measure until more data is collected in subsequent studies.

Concurrent Validity

In order to investigate concurrent validity, Spearman's rank correlation was used. The results from this analysis displayed several significant positive correlations between the two measures, particularly between the new measure and the communication and psychosocial sub-domains of the SAQOL-39. Similarly, Bose et al. (2009) found a significant positive correlation between the socialization and activities sub-domain of the QCL and the communication sub-domain of the SAQOL-39 ($r = 0.71, p = 0.05$). They additionally reported a significant positive correlation between the QCL mean and the communication sub-domain of the SAQOL-39 ($r = 0.73, p < 0.05$). The first finding was attributed to the fact that an individual's communication

abilities have an impact on various aspects of socialization, such as social network and activities (Bose et al., 2009). The second finding was attributed to the fact that the focus of the QCL is on the impact of an individual's communication disorder on various areas of life (Bose et al., 2009). As a result, these findings provided affirmation that the QCL measures what it purports. In line with the second finding, the overall score for the new HRQoL measure displayed significant positive correlations with both the communication and psychosocial sub-domains of the SAQOL-39 ($r = 0.707$ and $r = 0.623$ respectively, $p < 0.05$). Since the new measure is focused on aphasia-related deficits in the context of several psychosocial areas (i.e. emotional well-being, interpersonal relations, social inclusions, personal development, and self-determination), this finding serves as an affirmation that the new measure does capture the areas that it intends to. This conclusion is further supported by the large positive correlations seen between the psychosocial sub-domain of the SAQOL-39 and four of the previously outlined domains: emotional well-being, social inclusions, personal development, and self-determination ($r = 0.675 - 0.815$, $p < 0.05$). These correlations provide useful feedback on the content of these domains and additional support for their inclusion in the new measure.

On the other hand, significant negative correlations were seen between several domains of the new measure and the physical sub-domain of the SAQOL-39. During the assessment sessions with participants, it was clear that many of the participants felt much more impacted by one area after their stroke, either by their physical abilities or their communication abilities. This observation may account for these negative correlations since the new measure focuses on aphasia symptoms while the physical sub-domain of the SAQOL-39 focuses on an individual's physical limitations as a result of stroke. Since these domains measure different constructs, it is possible that this finding is representative of discriminant validity or evidence that one

questionnaire does not correspond to another due to a difference in what they assess. When investigating the relationship between the QCL and the SAQOL-39 in participants with aphasia, Bose et al. (2009) found a negative relationship between the physical sub-domain of the SAQOL-39 with both the socialization/activities and confidence/self-concept sub-domains of the QCL ($r = -0.03$ and -0.06 respectively). While these correlations were not significant, they do demonstrate that a negative or nonsignificant correlation is not uncommon for domains that measure different constructs. Therefore, the negative correlations from this analysis are not problematic.

However, a surprising finding was the significant negative correlation between the physical sub-domain of the SAQOL-39 and the physical well-being domain of the new measure. Since both of the domains pertain to physical health, a negative correlation is unexpected. While the SAQOL-39 focuses on physical functioning in relation to daily tasks (such as, the ability to open jars), the new QoL measure focuses on how physical health impacts an individual's life more generally (such as, participating in activities). Future work will need to further examine this relationship in a larger population and determine whether these six items should be more descriptive and specific to stroke.

Comparing between Groups

The Mann-Whitney U test was conducted to determine how participants with aphasia scored on the two measures of QoL compared with age-, gender-, and education-matched control participants. As hypothesized, participants with aphasia scored much lower than control participants on both measures of QoL. Consistent with previous findings (Bose et al., 2009; Manders et al., 2009), participants with aphasia obtained lower scores on all domains of the SAQOL-39, with the lowest score on the communication sub-domain. Participants additionally

scored lower on all domains of the new measure, with the lowest score on the material well-being and interpersonal relations domains.

In addition to this, there were differences between the group with aphasia and the control group in all areas. The U statistic value of 0 seen for both the communication sub-domain and overall score of the SAQOL-39 indicates that all of the participants from the control group scored higher in these two areas than all of the participants from the group with aphasia. In addition to this, the mean SAQOL-39 score for control participants ranged from 4.46 – 5.00 while the mean new QoL score for control participants ranged from 2.24 – 5.00. This finding may indicate that the new measure is sensitive to individual differences in a population in which communication deficits are not prominent.

Changes to the Measure

The findings from these analyses provide substantial evidence to support the removal of items 16, 23, and 28 from the measure. Observations from the interview and findings from the Spearman's rank correlation between the material well-being domain and the total score of the measure additionally provide support for the removal of items 14 and 15. Although the results from these statistical analyses provided information on the content of the items, the interview-based assessment sessions provided crucial information on the format of the measure.

Specifically, these assessments highlighted the aspects of the instrument that were favorable and the aspects that need to be refined.

Overall, the various steps taken to enhance the accessibility of the measure was one of the most beneficial aspects. Integrating these components into the measure enabled them to function in unison so that participants of various presentations and severities of aphasia could effectively follow along. Another beneficial aspect of the measure was the inclusion of the

summary question at the end. Of the 10 participants that completed this question, seven of them stated that they do believe that that future will be better while the remaining three indicated that they believed things would stay the same. While this item is not scored in the evaluation of HRQoL, it is very encouraging to see that a greater number of participants have remained optimistic, despite their experience. This question would be useful when working with an individual with aphasia in a one-on-one setting.

As previously mentioned, there are also some aspects of the measure that require refinement. Based on these sessions, it was evident that the visual aids and the visual analogue scale helped participants in understanding the content of the measure, particularly for participants that have difficulty reading. However, the images that were selected for items 4, 8, and 20 may need to be changed. Since these images show individuals engaging in highly physical activities, it was apparent that participants tended to focus on their physical impairments, until they were reminded otherwise. Although all images were pilot-tested, it was difficult to determine that this may be a problem until it was put into practice. In order to account for this in the future, the images for each item will be pilot tested again with a population that has aphasia. Their feedback will be used to select the most useful image for each item.

Another observation from the assessment session was the finding that participants understood the items more clearly when they were framed as questions. This was determined from the verbal prompts that the participants were given, as many of them were presented as questions. Considering this, and the length of the question stem, it may be advantageous to restructure the measure as a series of questions. An example item would be, "how often has your aphasia affected your ability to finish tasks?" If this structure was implemented, participants would need to be introduced to what aphasia means before beginning the first part of the

assessment and what physical health means before beginning the second part. A consistent example item for both sections would additionally help ensure that participants understand what they are being asked.

Next Steps

Subsequent studies will aim to collect more data so that a reliable PCA can be conducted and used to evaluate the structure of the measure more thoroughly. After this point, the relationship between the two measures can be re-evaluated in order to determine whether the physical well-being domain of the new measure focuses on the intended construct. The feedback provided by these analyses will enable us to make beneficial changes to the measure and determine when the measure has been refined. Once the measure has reached its finalized product, it can be used to evaluate the efficacy of various interventions, such as the Word Exchange groups that are run by the lab.

This study served as an essential step in the development of this measure. The steps taken to enhance the accessibility of the measure had a noticeable impact on each participant's ability to understand the content of the questionnaire and effectively self-report. This proved especially favorable for participants with severe forms of aphasia that would typically require a proxy to answer the questionnaire for them or be removed from the study altogether. In continuing efforts to increase the accessibility of this measure as well as the number of individuals with aphasia that are assessed, it is our hope that we will be able to construct a valid aphasia-specific HRQoL measure that is useful in evaluating individuals with a range of aphasia symptoms and severities. In creating this measure for this population of individuals, the goal is to better understand the hardships faced by individuals with aphasia and to account for the impact that deficits in communication place on various facets of an individual's life. It is our hope that we will be able

to use this information to pinpoint the areas that are most impaired and determine the means to best help this population.

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Appendix A

The Stroke and Aphasia Quality of Life Scale -39 (SAQOL-39)

The following items will be rated on a 5-point Likert scale, with 1 representing couldn't do it all, 2 representing a lot of trouble, 3 representing some trouble, 4 representing a little trouble and 5 representing no trouble at all.

During the past week, how much trouble did you have:

1. preparing food?
2. getting dressed?
3. taking a bath or shower?
4. walking? (If respondent can't walk, circle 1 and go to question 7)
5. keeping your balance when bending over or reaching?
6. climbing stairs?
7. walking without stopping to rest or using a wheelchair without stopping to rest?
8. standing?
9. getting out of a chair?
10. doing daily work around the house?
11. finishing jobs that you started?
12. writing or typing, i.e. using your hand to write or type?
13. putting on socks?
14. doing buttons?
15. doing a zip?
16. opening a jar?
17. speaking?
18. speaking clearly enough to use the phone?
19. getting other people to understand you?
20. finding the word you wanted to say?
21. getting other people to understand you even when you repeated yourself?

The following items will be rated on a 5-point Likert scale, with 1 representing definitely yes, 2 representing mostly yes, 3 representing not sure, 4 representing mostly no and 5 representing definitely no.

During the past week, did you:

22. have to write things down to remember them, (or ask somebody else to write things down for you to remember)?
23. find it hard to make decisions?
24. feel irritable?
25. feel that your personality has changed?
26. feel discouraged about your future?
27. have no interest in other people or activities?
28. feel withdrawn from other people?
29. have little confidence in yourself?
30. feel tired most of the time?
31. have to stop and rest often during the day?
32. feel too tired to do what you wanted to do?

- 33. feel that you were a burden to your family?
- 34. feel that your language problems interfered with your family life?
- 35. go out less often than you would like?
- 36. do your hobbies and recreation less often than you would like?
- 37. see your friends less often than you would like?
- 38. feel that your physical condition interfered with your social life?
- 39. feel that your language problems interfered with your social life?

Appendix B

Items Categorized by Domain for New Measure

First Domain: Emotional Well-Being

1. Ability to enjoy activities
2. Levels of stress
3. Self-esteem
4. Happiness

Second Domain: Interpersonal Relations

1. Motivation to interact with other people
2. Ability to maintain friendships
3. Ability to get along with your coworkers/peers
4. Ability to maintain a romantic relationship
5. Ability to meet new people

Third Domain: Social Inclusions

1. Motivation to join activities
2. Feeling of belonging to a social group
3. Motivation to attend events

Fourth Domain: Personal Development

1. Ability to finish tasks
2. Confidence in your abilities
3. Ability to learn new information
4. Feelings of competence
5. Ability to develop new skills

Fifth Domain: Self-Determination

1. Ability to make your own decisions
2. Ability to reach your goals
3. Ability to meet other's expectations
4. Ability to express opinions
5. Sense of independence

Sixth Domain: Material Well-Being

1. Job/volunteering opportunities
2. Ability to keep a stable job/volunteer position
3. Ability to control your own finances

Seventh Domain: Direct Communication

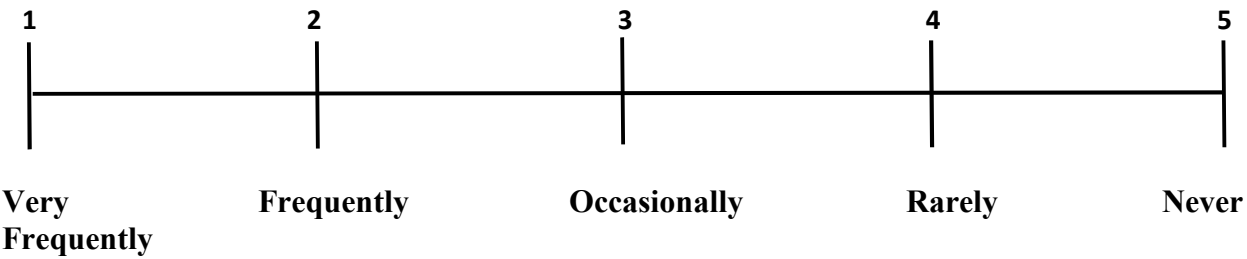
1. Ability to maintain a conversation
2. Ability to read
3. Ability to use the telephone

Eight Domain: Physical Well-Being

1. How often you go out
2. How much you sleep
3. Your energy
4. How much exercise you get
5. Your participation in activities
6. How you feel about yourself

Appendix C

Visual Analogue Scale



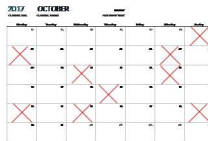
Very
Frequently



Frequently



Occasionally



Rarely



Never

Appendix D

Score Sheet

Part 1: In the past week, have your **aphasia symptoms** (your ability to speak or understand language) affected your:

Item #	Item	Rating (1-5) 1 =Very Frequently 2 =Frequently 3 =Occasionally 4 =Rarely 5 =Never	Notes
1	Ability to maintain a conversation		
2	Ability to read		
3	Ability to use the telephone		
4	Motivation to join activities Elaboration: Has this affected how much <u>you want</u> to do activities? Such as dancing, painting or cooking classes; key word = motivation		
5	Ability to enjoy activities Elaboration: Has this affected how <u>much fun</u> you have during these activities?		
6	Motivation to interact with other people Elaboration: Has this affected how much <u>you want</u> to interact with people? Such as wanting to talk or go out with friends; key word = motivation		
7	Ability to make your own decisions Elaboration: Has this affected your ability to decide what you want?		
8	Ability to reach your goals		

	Elaboration: Has this affected your ability to do something that's important to you?		
9	Ability to meet other's expectations Elaboration: Has this affected your ability to do what others expect of you? Such as following someone's instructions		
10	Ability to express opinions Elaboration: Has this affected your ability to tell others your opinion? Such as telling your family what you want for dinner		
11	Ability to finish tasks Elaboration: Has this affected your ability to finish something that you started?		
12	Confidence in your abilities Elaboration: Has this affected your confidence? Such as when you are doing an activity or speaking to someone		
13	Ability to learn new information Elaboration: Has this affected your ability to learn information? Such as names, phone numbers or facts		
14	Job/Volunteering opportunities Elaboration: Has this affected your ability to find a job/volunteer position?		
15	Ability to keep a stable job/volunteer position Elaboration: Has this affected your ability to <u>stay</u> at a work/ volunteer position?		
16	Ability to control your own finances Elaboration: Has this affected your ability to decide what to do with your money?		

17	Levels of stress		
18	Self-esteem Elaboration: Has this affected how good you feel about yourself or how much you value yourself as a person?		
19	Happiness		
20	Sense of independence Elaboration: Has this affected how much control you've had over your own life?		
21	Feeling of belonging to a social group Elaboration: Has this affected how well you relate to other people?		
22	Ability to maintain friendships Elaboration: Has this affected your ability to keep your friends?		
23	Ability to get along with your coworkers/peers Elaboration: Has this affected your relationship with your peers?		
24	Ability to be in a romantic relationship Elaboration: Has this affected your relationship with your partner/spouse?		
25	Motivation to attend events Elaboration: Has this affected how much you <u>want to</u> go to events? Such as dinner parties or weddings		
26	Ability to meet new people Elaboration: Has this affected your ability to meet people? Such as introducing yourself to someone or starting a conversation		
27	Feeling of competence		

	Elaboration: Has this affected how skilled or capable you have felt?		
28	Ability to develop new skills Elaboration: Has this affected your ability to learn new skills? Such as learning new games		

Part 2: In the past week, has your **physical health** affected:

Item #	Item	Rating (1-5) 1 =Very Frequently 2 =Frequently 3 =Occasionally 4 =Rarely 5 =Never	Notes
1	How often you go out		
2	How much you sleep		
3	Your energy		
4	How much exercise you get		
5	Your participation in activities		
6	How you feel about yourself		
Overall	Do you expect the future to be better?		

Appendix E

Participant Copy of the QoL Measure

Part 1: In the past week, have your **aphasia symptoms** (your ability to speak or understand language) affected your:

1. Ability to maintain a conversation



2. Ability to read



3. Ability to use the telephone



In the past week, have your **aphasia symptoms** (your ability to speak or understand language) affected you:

4. Motivation to join activities



5. Ability to enjoy activities

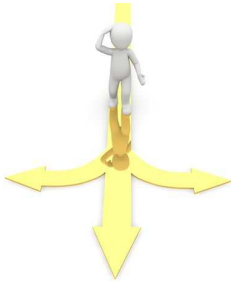


6. Motivation to interact with other people

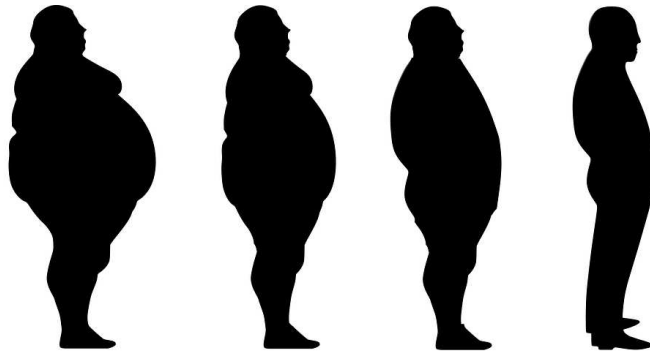


In the past week, have your **aphasia symptoms** (your ability to speak or understand language) affected your:

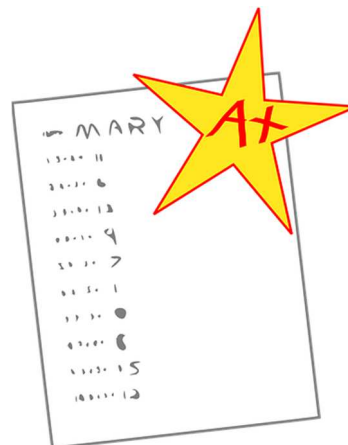
7. Ability to make your own decisions



8. Ability to reach your goals



9. Ability to meet other's expectations



In the past week, have your **aphasia symptoms** (your ability to speak or understand language) affected your:

10. Ability to express opinions



11. Ability to finish tasks

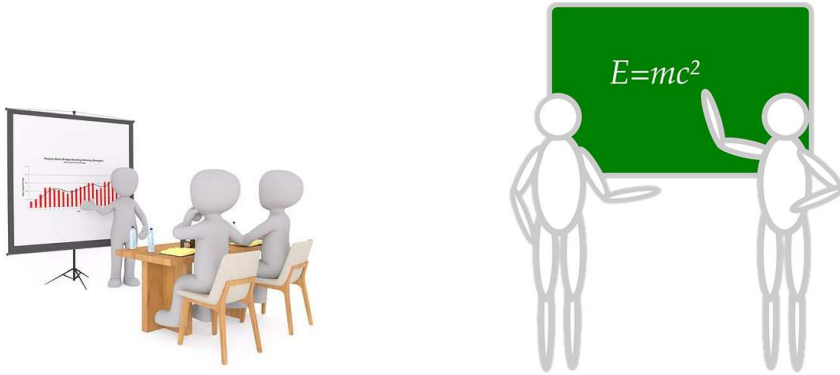


12. Confidence in your abilities



In the past week, have your **aphasia symptoms** (your ability to speak or understand language) affected your:

13. Ability to learn new information

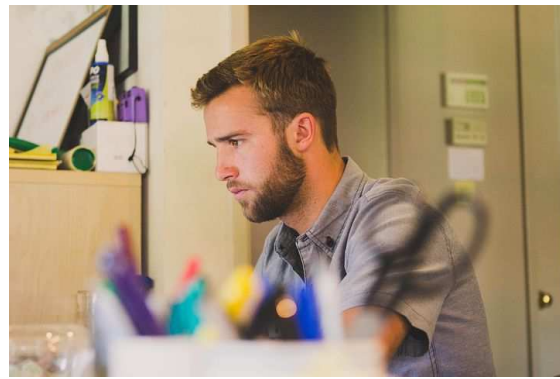


14. Job/Volunteering opportunities



In the past week, have your **aphasia symptoms** (your ability to speak or understand language) affected your:

15. Ability to keep a stable job/volunteer position



16. Ability to control your own finances



17. Levels of stress



In the past week, have your **aphasia symptoms** (your ability to speak or understand language) affected your:

18. Self-Esteem



19. Happiness



20. Sense of Independence

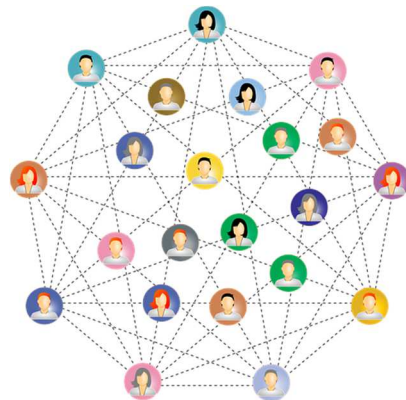
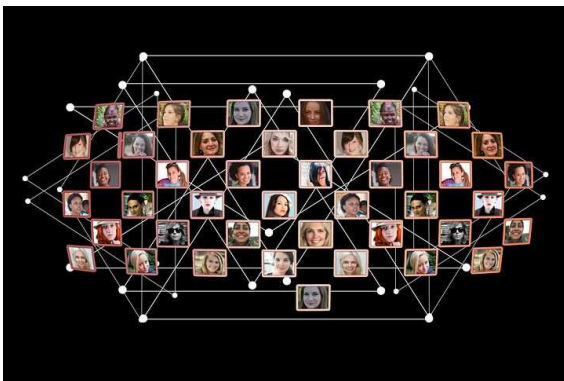


In the past week, have your **aphasia symptoms** (your ability to speak or understand language) affected your:

21. Feeling of belonging to a social group



22. Ability to maintain friendships



23. Ability to get along with your coworkers/peers



In the past week, have your **aphasia symptoms** (your ability to speak or understand language) affected your:

24. Ability to be in a romantic relationship



25. Motivation to attend events



26. Ability to meet new people



In the past week, have your **aphasia symptoms** (your ability to speak or understand language) affected your:

27. Feelings of competence



28. Ability to develop new skills



Part 2: In the past week, has your **physical health** affected:

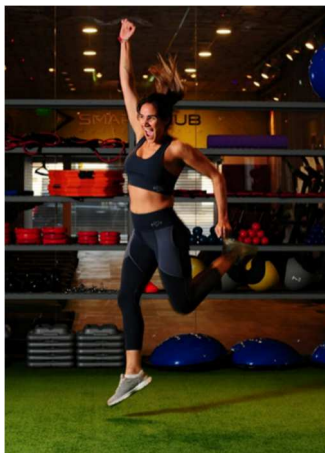
1. How often you go out



2. How much you sleep



3. Your energy



4. How much exercise you get



5. Your participation in activities



6. How you feel about yourself



Overall: Do you expect the future to be better?

Appendix F

Introductory Questions

On a scale of 1-5 (with 1 representing very poor, 2 representing poor, 3 representing adequate, 4 representing good and 5 representing excellent), how would you rate your:

1. Ability to read in English
2. Ability to write in English
3. Ability to speak in English
4. Ability to understand English

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